

# Improving Primary Care for Persons with Disabilities: the nature of expertise

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**ABSTRACT** *It has been well documented that persons with disabilities (PWDs) have a more vulnerable health status than persons without disabilities; yet, they often receive inadequate primary care within the US health care system. This study explores how PWDs think about the health care they receive, particularly how primary care providers facilitate or hinder quality care for PWDs. The findings from this study expand the concept of expertise in health care, suggesting it goes well beyond technical competence of health care providers. For PWDs, expertise is multi-dimensional, not solely the domain of providers and includes having knowledge and using that knowledge within the context of the provider–patient relationship. PWDs identified three distinct areas of expertise: medical/technical, medical/biographical, and systems. Expertise can be brought to health care encounters by both PWDs and providers, and it can be developed through collaboration during interactions between providers and PWDs.*

## Introduction

In the United States the provision of health promotion and disease prevention services in clinical settings by general and family practitioners, general internists and paediatricians is known as primary care. Patients seek care from primary care providers in the US much like patients in the United Kingdom (UK), and other developed nations utilise the services of a general practitioner (GP). It has been well documented that persons with disabilities (PWDs) have a more vulnerable health status than persons without disabilities (Batavia *et al.*, 1988–89; Pope & Tarlov, 1991; Sutton & DeJong, 1998; DeJong *et al.*, 2002). Yet, community-living PWDs in the US receive inadequate health promotion and disease prevention services

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within the health care system (DeJong *et al.*, 2002; Iezzoni, 2002; US Department of Health & Human Services, 2000).

In the US, PWDs who seek primary care services encounter a range of obstacles to receiving quality primary care (Seekins *et al.*, 1994; Brandt & Pope, 1997; DeJong, 1997; DeJong & Frieden, 2002). Types of barriers are physical, social and economic (DeJong *et al.*, 2002), the most significant of which include: 'transportation difficulties, inaccessible offices, inadequate provider knowledge, provider attitudes, and inadequate medical insurance coverage' (Gans *et al.*, 1993, p. S-16).

Physical barriers frequently are a problem (Anderlik & Wilkerson, 2000; Nosek, 2000; DeJong *et al.*, 2002). For example, in the US, a recent lawsuit against a large health care system alleged that many of its medical facilities are in violation of the Americans with Disabilities Act. The plaintiffs, represented by a disability rights advocacy group, claim that it is common for PWDs to receive substandard care because doctors' offices and clinics often lack accessible exam tables and scales, and because narrow doorways and cluttered exam rooms prevent entry for wheelchair-bound consumers (Glionna, 2000).

Social barriers include inadequate provider knowledge or lack of 'disability literacy' or 'disability competence' in care settings (DeJong & Frieden, 2002, p. 5). As noted by Batavia *et al.* (1988–89), PWDs often find that 'physicians unfamiliar with disability-related care focus inappropriately on their disabilities per se, rather than on the presented health problem' (p. 10), thus undermining primary care. Provider lack of knowledge then becomes the PWD's problem—'people with disabilities must repeatedly educate primary care physicians about the nature of their disabilities' (Batavia *et al.*, 1988–89, p. 10). These social barriers are not exclusive to the US. Begum (1996) and Whitehead & Williams (2001) found that women with disabilities in the UK often did not feel that their providers listened to them or included them in treatment decisions. PWDs report that office staff and health care providers often treat them with disdain; for example, not allowing enough time for appointments, ignoring PWDs or not communicating with them directly (DeJong *et al.*, 2002; O'Day *et al.*, 2002).

Other barriers are economic. A recent survey of PWDs in the US found that they were more than twice as likely as people without disabilities to postpone seeking health care because they lacked the money to pay and were four times as likely to have health needs that were not covered by insurance (National Organisation on Disability, 2000). The combination of physical, social and economic barriers makes it difficult for many PWDs to receive high quality health care.

The adverse effects of these combined barriers have been particularly well documented in the area of preventive care. In a 4-year study in the US by the Rehabilitation Research and Training Center on Managed Care and Disability, researchers found that working-age PWDs were less likely than non-disabled groups to receive preventive services, such as smoking cessation counselling, gynecological services and information about contraception (DeJong & Frieden, 2002). These latter findings were supported by several other studies reporting that disabled women are significantly less likely than able-bodied women to receive screening tests

like mammograms and pap smears (Nosek & Howland 1997; 'Use of Cervical & Breast Cancer Screening', 1998; Chan *et al.*, 1999; Iezzoni *et al.*, 2000).

The consequences are significant. Studies have shown that persons with spinal cord injuries in particular have very high rates of rehospitalisation shortly after discharge from rehabilitation facilities (American Congress of Rehabilitation Medicine (ACRM), 1993). An epidemiologic study of PWDs residing in a rural area of the Western United States showed high occurrence rates of 'secondary conditions' like pressure sores and urinary tract infections (Seekins *et al.*, 1994). The authors noted that many of these conditions are highly preventable.

Barriers to quality primary care services often lead PWDs to attempt self-treatment that is unsuccessful (Batavia *et al.*, 1988–89) and/or force them to seek help from specialists (ACRM, 1993), further compounding the problem of inadequate primary care. Not incidentally, these patterns of resort result in more secondary conditions and increased health care costs (Brandt & Pope, 1997).

The research reported here was designed to explore how PWDs think about the health care they receive; in particular, how PWDs evaluated the quality of the care they received from their primary care providers. The key finding is the expanded concept of 'expertise' in facilitating high quality primary care for PWDs. While expertise is always an important component of care quality, the nature of expertise is different for PWDs. The purpose of this article is to describe how PWDs defined expertise and how they perceived that expertise, or the lack of it, influenced the quality of primary care services.

## **Methods**

A multidisciplinary team of researchers used grounded dimensional analysis (Glaser & Strauss, 1967; Strauss, 1987; Schatzman, 1991; Caron & Bowers, 2000), a theory-generating approach, to collect and analyse data. The method combines the grounded theory methodology developed by Glaser & Strauss (1967) with dimensional analysis (Schatzman, 1991; Caron & Bowers, 2000), resulting in a systematic framework for the analysis of grounded data. Data were gathered through in-depth in-person and online interviews. Analysis was iterative and involved the entire team.

After researchers obtained approval from the University of Wisconsin-Madison, Health Sciences Human Subjects Office to conduct research with human subjects, data collection began. Electronic (online) interviews were conducted with 19 disabled adults and seven parents of disabled children. These participants were recruited from online list-servs (including C-Palsy, Our Kids, Mobility and Teamwork) established by and for individuals with a range of disabilities. Use of electronic interviewing allowed for the inclusion of individuals whose disabilities or geographic distance would have prevented them from participating in face-to-face interviews. In order to ensure the inclusion of wider income and educational representation than found through the listserv membership, 16 PWDs from a community-based case management programme for individuals eligible for publicly funded insurance were recruited to participate in face-to-face interviews.

List-serv participants were sent three questions at a time, allowing them the

freedom to respond in as much detail as they wished before being sent follow-up questions. Electronic interviewing of individuals took place over a period of weeks, with some interviews lasting as long as several months. Participants recruited from the community-based programme participated in face-to-face interviews, which generally lasted an hour. Data were collected over a period of 2 years, from 1995 to 1997.

Participants were informed that the researchers were conducting a study of health care for people with severe physical disabilities. The researchers emphasised that they wanted to hear what, from the participants' perspective, was important to understand about the quality of care. As is required in theory-generating research, early interview questions were very open and unstructured, allowing the participant to define the phenomena under study. As the study proceeded, interviews retained the openness, but more focused questions, generated from the analysis of prior interviews, were added. This maintained the discovery purpose, but allowed the investigators to bring depth and complexity to areas found relevant across participants. Analysis of these data led to a new set of questions focusing on issues such as the specific ways in which the presence or absence of collaborative (patient/provider) decision-making affected the quality of the care experience.

The 42 individuals (20 males and 22 females) who participated in the project included 35 adults with physical disabilities and seven parents of children (under 18 years old) with physical disabilities. Disabilities included spinal cord injuries, chronic degenerative conditions (such as multiple sclerosis), amyotrophic lateral sclerosis, congenital disorders (such as cerebral palsy), spina bifida and other chronic disabling conditions (such as asthma, heart disease and post-polio syndrome). The length of time living with a disability ranged from 18 months to more than 40 years, with 88% of the respondents ( $n = 37$ ) living with disability for more than 5 years. Participants reported a wide range of insurance coverage encompassing private employer-based (including managed care) to publicly funded insurance for severely disabled individuals. Two participants did not provide information about their insurance coverage/s. No correlations were found between subject demographics and care experiences; these experiences were strikingly similar across the entire group.

## **Results**

The findings from this study expand the concept of expertise in health care, suggesting that expertise is something that includes, but goes well beyond the technical competence of health care providers. For PWDs, expertise is multi-dimensional. Expertise is about having knowledge and using that knowledge within the context of the provider-patient relationship. PWDs identified three distinct areas of expertise, medical/technical, medical/biographical and systems that were necessary for high quality care. Finally, expertise is brought to health care encounters by both PWDs and providers, and is developed through collaboration during interactions between providers and PWDs. This paper describes the elements of expertise, in particular highlighting the range of provider expertise that was identified as being

essential to high quality care. It also provides examples of the kinds of personal expertise that PWDs bring to patient-provider interactions.

### **Dimensions of Expertise**

For these PWDs, expertise has two primary dimensions. First, expertise is about having knowledge. That is, a ready collection of facts and skills that goes beyond general medical knowledge about health and illness. Secondly, expertise is about using knowledge. Using knowledge includes being willing and able to deploy knowledge in the context of the patient's life. That is, possessing and using insight about which fact or skill is appropriate to a particular patient's situation. It also includes using knowledge collaboratively with patients in treatment decisions, integrating the knowledge and preferences that PWDs bring to the patient-provider interaction even if it is inconvenient or otherwise problematic for the provider to do so. According to the PWDs who participated in this study, expertise exists only if the provider respects the patient, and provides opportunities for the patient or patient's representative to collaborate in decisions about care and treatment.

The following quotations, the first from the parent of a disabled child and the second from an adult with physical disabilities, show the integration of these dimensions of expertise within the context of primary care in the US:

I think of three things when I think of 'high quality care': One, diagnosis; two, informed choice; three, skill. First, I want a timely and accurate diagnosis from which to work. Secondly, I want my options outlined in terms I can understand with benefits weighed out against risks for me so I can make an informed choice in the best interests of my child or myself. Thirdly, I want all treatment carried out by medical professionals with a skill level high enough to reduce and minimise any risks associated with the treatment or the procedure. If I can't find these three components of health care then I'm at the wrong doctor's office.

I evaluate my healthcare providers primarily on several bases: the degree they act as if I am smart and capable of making my own ultimate decisions; the extent of their knowledge and their ability to present it to me; evidence that they respect and value me as a person.

### **Areas of Expertise**

According to PWDs, providers needed to have and use knowledge in three distinct, but inter-related areas. The three areas of expertise included medical/technical, medical/biographical and systems expertise. According to the PWDs in this study, expertise exists, and therefore high quality care is likely to result, when all three areas of expertise are considered during health care decision making. Decisions made with consideration for only one area of expertise were described by PWDs as leading to lesser quality care.

*Medical/Technical Expertise*

Medical/technical expertise consists of medical skill and knowledge about health and illness, including general diagnostic skills, knowledge about primary care, and competence in medical management of acute and chronic illnesses. However, more importantly, providing primary care to PWDs also includes having specialised knowledge about specific conditions or disabilities and how they relate to or influence the course of other illnesses. According to PWDs, the most important elements of this specialised knowledge are:

- the ability to manage primary care and prevention in the context of the disabling condition;
- an awareness of cutting-edge treatments;
- a familiarity with available adaptive technology for PWDs.

Particular examples include the ability to recognise and treat urinary tract infections in persons with spinal cord injuries, and the skill and knowledge to know when and how to perform pelvic examinations on women with spasticity due to cerebral palsy. Although medical/technical expertise is a necessary component of high quality primary care, alone it is not sufficient to provide such care.

*Medical/Biographical Expertise*

Medical/biographical expertise is knowledge about the intersection of illness and/or disability with the life of the individual. This expertise has two components:

- knowledge of how the bodies of individuals respond to common illnesses and medical interventions (for example, one participant described how she had come to know when she was developing bowel or bladder problems by the (idiosyncratic) goosebumps she developed at these times.);
- an understanding of the impact that disability, illness, and treatment interventions may have on quality of life.

While illnesses like colds or urinary tract infections may be without serious consequence for most people, they can have tremendous negative impact for PWDs, resulting in secondary complications, lengthy recovery times, and severe disruptions to work, relationships, family life and other daily activities.

PWDs in this study reported that high quality primary care requires the integration of medical/technical expertise and medical/biographical expertise. That is, PWDs want their providers to know the particularities of their bodies, their conditions, and their responses to illness and treatment. They want providers to remember what has worked for them in the past and use that knowledge to predict what is likely to work in the future. They also expect providers to be able to think holistically about the impact that their medical recommendations and decisions will have on their patients' lives, overall. The following quotation illustrates these expectations:

Our primary care physicians are very caring and involved. They treat [my

daughter] as a ‘whole person’ and strive to afford her every opportunity to achieve her potential and to meet her needs. They are also very considerate of our family dynamics and the other demands on our time and resources.

### *Systems Expertise*

Systems expertise is knowledge and skill related to accessing, using and managing multiple provider and/or service systems (e.g. health, social, transportation) simultaneously. It includes:

- knowing how different services are organised and distributed;
- understanding rules and policies;
- learning the authority structures of each system;
- finding back doors to access services;
- being able to effectively use gate-keeping mechanisms to devise short cuts or make exceptions.

PWDs need providers who have and will use systems expertise to promote the efficient, timely, convenient, and non-disruptive delivery of services across systems for their patients. The following quotation illustrates a provider’s use of systems expertise:

Most [consumers] seem to choose scooters, but after research I realised it wasn’t for me. My [primary care provider] was helpful—I told him I wanted to ‘test drive’ the e-chair for at least a month before buying and he helped me run interference with the [durable medical equipment] bean counter (*accountant*) at my [Health Maintenance Organisation]. [Authors’ italics]

### **Sources of Expertise: individual and collaborative**

There are two sources of expertise. Expertise is brought to health care encounters by the individuals involved, that is, the provider and the patient and/or the patient’s representative. It is also developed through collaborative, reciprocal interactions between providers and patients that take place over time. While individual sources of expertise demonstrate successful ‘learning about’, collaborative sources of expertise demonstrate the ability to ‘learn with’. Providers and PWDs each can bring and develop medical/technical, medical/biographical and systems expertise.

For providers, medical/technical expertise derives from general knowledge about health and illness, and the impact of disability on both. Although medical/technical expertise often is perceived as being part of the provider’s domain, many PWDs in this study described how they also bring medical/technical expertise to interactions with their providers. PWDs become a source of medical/technical expertise through the experience of living with the condition, and also through literature searches, Internet research and talking with others who have similar

conditions. PWDs expect that providers will listen and respond to the medical/technical expertise that they (PWDs) bring to the patient-provider interaction.

For PWDs, medical/biographical expertise typically is obtained through years of living with their disabilities. Providers' medical/biographical expertise, however, is acquired in several ways. Ideally, it results from a provider's long-term familiarity with his/her patients. (Unfortunately, disruptions to long-term patient/provider relationships resulting from a variety of system problems may leave a PWD without a provider who has medical/biographical expertise.) This expertise also can be acquired through careful examination of well-documented medical records.

Medical/biographical expertise also is developed through reciprocity. It can be developed when the provider uses a highly collaborative and trusting style of interaction with PWDs. However, when it is developed through reciprocity, patients must be willing to take on the task of instructing providers in the specifics of their conditions and lives, while providers must be willing and able to learn from their patients.

PWDs gain systems expertise over time and through the experience of managing services from multiple systems that are necessary for living with their disabling conditions. However, PWDs often lack the authority to effectively access and co-ordinate essential services within and across multiple systems. Providers, on the other hand, are perceived by PWDs as having the ability and authority to navigate and negotiate, within and between, particular systems. Providers can bring systems expertise that they have acquired through experiences with various delivery systems. They can also develop systems expertise by listening to and learning from the experiences of their patients, in particular PWDs. Successful deployment of systems expertise requires medical/biographical expertise—that is, an understanding of the particularities of each individual's needs and how they wish to use services.

### **When Provider Expertise is Lacking**

According to the PWDs in this study, ideal high quality primary care centers on having one provider who has and integrates knowledge from all three areas of expertise described above. Unfortunately, participants in this study reported that it was exceedingly rare to find such providers. In fact, many reported that finding a provider with even basic medical/technical expertise was often very difficult, as these quotes illustrate:

I have in my experience come upon physicians who just do not know the first thing about how to care for a person in my condition, with a severe disability like mine ... if you don't know what to do, if you don't know that first damn thing about what to do, you're just no damn good to the patient!

There are just too few specialists available that my daughter needs. I know, as do most handicaps or their caregivers, what type of physician is required. I don't want to nor do I go through a general practitioner so that I may see an orthoped (orthopedic specialist) for my daughter. General practitioners are just not knowledgeable enough. So the real bottom line is availability of



doctors who treat handicapped people and are therefore familiar with the subtleties of their syndromes. [Authors' italics]

As a result, PWDs described strategies they developed to compensate for the expertise that they perceived their providers lacked. One strategy was to find the most congenial, accessible, collaborative provider available and to endure the technical deficits that might result from his/her lack of medical/technical expertise:

My primary care doctor is a doll. She treats me with respect and always lets me be involved in decisions, asking 'and what do you think?' Although she is wonderful in that way, she doesn't have much knowledge concerning spinal cord injuries, which sometimes bothers me as I wonder if I might get better care from a specialised doctor.

A second strategy was for PWDs to utilise their own systems expertise to locate and consult with a number of different providers, each of whom had one particular type of medical/technical expertise. Even when used successfully, this strategy required a great deal of management work on the part of the PWD, often resulting in a lack of integration across the range of providers and treatment delays:

Doctors pretty much have to grant what I ask or I'll go to another, but sometimes this gets tricky. For example, my current ortho(*pedic*) doctor wrote a prescription for the new wheelchair but wouldn't prescribe [certified nursing assistant] care. I went to an internist for that ... These doctors don't know about each other. [Authors' italics]

A third strategy was for PWDs to set about teaching their providers what they thought providers needed to know in order to provide quality of care:

I prepare a 'where I am now' report for each visit, with a section on current drugs (how they're tolerated, do I need refills ...); things that have changed, things that stay the same, research update (I'll tell you [provider] what I've read and snagged from the net, you [provider] react), plan for next visit.

A fourth strategy, also very common, was for PWDs to develop and substitute their own expertise for that perceived to be lacking in their providers. PWDs in this study reported locating and reading the most up-to-date research they could find, learning the interworkings of the various service systems and formulating their own care plans. In doing so, PWDs often substituted their own expertise for a deficiency of medical/technical expertise in their provider:

I recently saw my general practitioner for recurrent back pain. I had to do my own research in order to locate a new medication to try. Even after I did the research, he was extremely reluctant to allow me to try it, saying it would probably not work, but reluctantly wrote a prescription. I have been pain free for the last year.

They substituted it for a deficiency in provider medical/biographical expertise:

One orthopedist ... had preconceptions. [He said] 'We'll do her surgery in

the summer so she won't miss school.' Oh yeah? [My daughter] was in kindergarten, how much could missing school matter? He wanted her to miss swimming and sunshine and sand?

And they substituted it for a deficiency in provider systems expertise:

Because I'm quite assertive, I can usually make my way through whatever system is put before me. For example, last year I made physical therapy appointments for my kids with the physical therapist we had been seeing. Because the kids were both [medical assistance eligible] we received a call changing the appointments I had so carefully set up and [I] was told that different physical therapists handled the [medical assistance] cases. I demanded that they bump two other patients as they had bumped my kids so that they could get their physical therapy eval(uation)s done by the same person in a timely manner. They got us in. If they hadn't, I could've gone up the chain of command until I got what I figured they deserved. [Authors' italics]

Each of these compensatory strategies PWDs described using could (and often did) result in significant and adverse consequences. For example, when PWDs 'settled' for a pleasant, respectful provider who lacked medical/technical expertise, but was willing to collaborate, they were not likely to receive state-of-the-science care and suffered needlessly due to the provider's lack of knowledge about relevant interventions:

We have a primary care provider (who knows nothing at all about spinal cord injuries). He prescribes medicine that causes bloodclots or causes muscle relaxation or wants to sedate me all day, just to name a few.

Those participants whose providers lacked systems and medical/biographical expertise were forced to cobble together their own web of expertise, spending precious time, money and energy on this work, which adversely affected their quality of life. Furthermore, when formal systems broke down, these participants had to develop their own back-up systems, e.g. drawing on the (often limited) good will and time of family, friends, or neighbors for assistance. In essence, many of these PWDs, out of necessity, became their own case managers and developed elaborate back up systems.

When PWDs developed their own expertise and attempted to share this with providers, it required time and energy that could be found only by diverting it from other activities. They also risked antagonising their providers if their (PWDs) information was found to be inaccurate or drawn from sources a provider considered unreliable. Faced with the choice of using limited resources and being overwhelmed by the task of continually repeating or fighting for their needs, many PWDs described how sometimes they 'opted out' of the health care system altogether, turning to alternative medicine or choosing not to seek the care they needed until they were so sick that they had no other options. This kind of opting out resulted in serious, sometimes life-threatening consequences.

## **Discussion**

PWDs describe the process of accessing primary care as a kind of Hobson's choice: because it is so rare to find one provider who has knowledge in all of the areas described as being essential to high quality primary care, PWDs often have to prioritise and choose among the areas, and/or develop their own expertise as a supplement for what is missing. Some choose technical knowledge and competence in a provider over willingness to collaborate; others choose a provider who is able to 'work' the system over those who have either technical competence or a willingness to collaborate. Still others choose congeniality and willingness to collaborate over competence. Each of these choices is likely to result in serious and negative consequences for PWDs.

The notion of expertise to emerge from this research requires a reconceptualisation of the definition held by most providers. Those with medical training tend to think of expertise as technical competence, the presence or absence of which can be judged by clinical outcomes. Traditionally, provider expertise also is believed to increase as detachment and objectivity increase. Disciplinary training is seen as the source of this kind of expertise. By contrast, PWDs see expertise as multi-faceted and as originating with both patients as well as providers. Expertise encompasses technical knowledge, but it also includes the realm where real life interacts with disability, requiring a collaborative interaction between patient and provider. Furthermore, it focuses as much on the organisation of services as it does on the technical quality of health care. PWDs use clinical outcomes in their assessments of expertise, but just as important are quality of life outcomes like time and energy saved—and the living that can be accomplished as a result—outcomes that are inherently subjective. 'Doctor-shopping', failure to comply with treatment plans and self-management are predictable outcomes of patient frustrations related to incomplete provider expertise.

These findings have implications for PWDs in the US system, as well as other systems in developed countries. They indicate that GPs and other primary care providers would be more effective for PWDs if they expand on what is generally considered their area of expertise, taking on dimensions of expertise traditionally considered to be the domain of specialists.

It is important to note that the findings described here are based on a population of PWDs who, for the most part (88%), had been living with their disabilities for more than 5 years. Therefore, although the perspectives of these participants on evaluating the quality of primary care were remarkably consistent, the applicability of the findings to newly disabled patients or wider patient populations has not been tested. It is also important to emphasise that the focus of this study was to explore the perspectives of PWDs on how providers influenced the quality of primary care. We encourage additional comparative research designed to examine providers' perspectives around these same issues.

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